

Hospice and Palliative Care

See Also: [Caregiver Resources](#), [Mental Health and Aging](#), [Suicide and the Elderly](#),
[Spirituality and Aging](#)

There are few more controversial issues related to the well being of older adults than end-of-life care. Professional caregivers cope with ethical, moral and legal conflicts in diagnosis and treatment of patients with terminal health conditions. Health care administrators, insurance professionals, and public policy officials debate the value and limits of high tech life-extension technology. Older adults worry that their advance directives may not be honored and family members are stressed by the burden of making surrogate decisions for their loved ones on continuation of testing and treatment or increasing pain management and initiating hospice care. Links on this page lead to description and discussion on all of these issues.

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Consumer Fact Sheets

What is Hospice?

(National Hospice and Palliative Care Organization)

<http://www.hospiceinfo.org/public/articles/index.cfm?cat=2>

Advance Care Directives and Do Not Resuscitate Orders

(American Academy of Family Physicians)

<http://familydoctor.org/handouts/003.html>

Four Levels of Care Your Entitled to Receive

(Hospice Patients Alliance)

<http://www.hospicepatients.org/hospic20.html>

The Medicare Hospice Benefit

(Center for Medicare Education)

<http://www.medicareed.org/content/CMEPubDocs/V2N9.pdf>

Medicare Hospice Benefit

(National Hospice Foundation)

<http://www.hospiceinfo.org/public/articles/index.cfm?cat=7>

Family Worksheets – Questions About End-of-Life Care

(Hospice Patients Alliance)

<http://www.hospicepatients.org/hospic63.html>

Find a Hospice

(National Hospice and Palliative Care Organization)

<http://www.hospiceinfo.org/public/articles/index.cfm?cat=23>

Home Care/Hospice Agency Locator

(National Association for Homecare)

<http://www.nahc.org/Tango/HCLocator/locator.html>

Problems and Complaints About Hospice – What to Do

(Hospice Patients Alliance)

<http://www.hospicepatients.org/hospic45.html>

How Do We Pay for End of Life Care?

(Alliance for Aging)

http://www.allhealth.org/pub/pdf/12_01AHRv6.pdf

Hospice Care

Hospice Net

<http://www.hospicenet.org/>

Hospice Home Page

(Santa Clara University)

<http://www.scu.edu/Hospice/>

Hospice Services under Medicare

(U.S. Centers for Medicare and Medicaid Services)

<http://www.cms.hhs.gov/medlearn/refhospice.asp>

Paying for Hospice Care

(Public Policy Institute, AARP)

http://research.aarp.org/health/fs81_hospice.html

Hospice Patients Alliance

<http://www.hospicepatients.org/>

End-of-Life Care in Managed Care Organizations -- Executive Summary

(Public Policy Institute, AARP)

http://research.aarp.org/health/9908_end_1.html

Palliative Care

Management of Persistent Pain – Resources for Older Adults and Caregivers

(AGS Foundation for Health in Aging)

http://www.healthinaging.org/public_education/pain/

Palliative Care

(Health Canada, Division for Aging and Seniors)

<http://www.hc-sc.gc.ca/english/care/palliative.html>

Spirituality in Palliative Care

(Geriatric Times)

<http://www.geriatrictimes.com/g021225.html>

Palliative Care and A Caregivers Guide

(Alberta Palliative.Net)

<http://www.albertapalliative.net/APN/CGG/CGGIdx.html>

Pain.Com – A World of Information on Pain

<http://www.pain.com/>

Pain Management

(OncoLink , U. of Pennsylvania)

<http://cancer.med.upenn.edu/psychosocial/>

Grief (Death and Dying)

Death and Dying – Medline Plus

(National Library of Medicine)

<http://www.nlm.nih.gov/medlineplus/deathanddying.html>

Grief and Loss – A Collection of Resources

(AARP)

<http://www.aarp.org/griefandloss/>

Beyond Indigo – Changing the Way You Feel About Grief and Loss

<http://www.death-dying.com/>

GriefNet

<http://www.rivendell.org/>

Grief Recovery Institute

<http://www.grief-recovery.com/>

Grief Recovery On-Line

<http://www.groww.org/>

Legacy.com

<http://www.legacy.com/legacyhome.asp>

Sociology of Death and Dying

<http://www.trinity.edu/~mkearl/death.html>

National Forums and Advocacy Organizations

Americans for Better Care of the Dying

<http://www.abcd-caring.org/>

Circle of Life Award – Celebrating Innovation in End of Life Care

(American Medical Association)

<http://www.aha.org/circleoflife/>

Facts on Dying - Policy Relevant Data On Care At The End Of Life

(Center for Gerontology and Health Care Research, Brown University)

<http://www.chcr.brown.edu/dying/factsondying.htm>

Fairy Godmother Foundation

<http://www.fairygodmother.org/>

Growth House, Inc.

<http://www.growthhouse.org/>

The Complete Life Course

(Kokua Mau)

<http://www.kokuamau.org/tools/complete.htm>

Last Acts – A National Coalition to Improve the Care and Caring at the End of Life

<http://www.lastacts.org/>

Last Chapters

<http://www.lastchapters.org/>

On our Own Terms - Moyers on Dying

(PBS)

<http://www.pbs.org/wnet/onourown/terms/about/>

Partnership for Caring

<http://www.partnershipforcaring.org/HomePage/>

Project on Death in America

(Open Society Institute)

<http://www.soros.org/death/index.htm>

Rallying Points

Improving Community End of Life Care Through Coalitions

<http://www.rallyingpoints.org/>

Right to Die – Public Agenda on Line

http://publicagenda.org/issues/frontdoor.cfm?issue_type=right2die

Widow Net

<http://www.fortnet.org/WidowNet/>

With Eyes Open

(PBS)

<http://www.pbs.org/witheyeyesopen/>

Advance Care Directives

Consumers Tool Kit for Advance Care Directives

(American Bar Association)

<http://www.abanet.org/aging/toolkit/>

Shape Your Health Care Future with Health Care Advance Directives

(American Medical Association)

<http://www.ama-assn.org/public/booklets/livgwill.htm>

Advance Care Planning: Medical Care at the End of Life

(American Academy of Family Physicians)

<http://www.aafp.org/afp/990201ap/990201b.html>

Overview of Advance Care Planning

(Dorothy Garske Center)

<http://www.dgcenter.org/acp/acpOverview.htm>

Advance Directives (Forms for states in pdf. format require registration but no fee)

(Partnership for Caring)

<http://www.partnershipforcaring.org/Advance/index.html>

Five Wishes (Form is valid in 33 states)

<http://www.agingwithdignity.org/5wishes.html>

Government Reports and Testimony

Advance Care Planning: Preferences at the End of Life

(Agency for Healthcare Research and Quality)

<http://www.ahrq.gov/research/endliferia/endria.htm>

Improving Palliative Care for Cancer: Summary and Recommendations

(National Academy of Science)

<http://www.nap.edu/books/0309075637/html>

Quality Of Life Includes Death: Health Minister (Australia)

(Australian Department of Health and Aging)

<http://www.health.gov.au/mediare/yr2003/kp/kp03075.htm>

Improving Palliative Care for Cancer: Uncorrected Proof

(National Academy of Science)

http://search.nap.edu/html/palliative_care/

Synthesis and Analysis of Medicare's Hospice Benefit Executive Summary and Recommendations

(Assistant Secretary for Planning and Evaluation,
Department of Health and Human Services)

<http://aspe.hhs.gov/daltcp/reports/samhbes.htm>

Medicare: More Beneficiaries Use Hospice; Many Factors Contribute to Shorter Periods of Use, T-HEHS-00-201, September 18, 2000

<http://www.gao.gov/new.items/he00201t.pdf>

Barriers to Hospice Care – Are We Shortchanging Dying Patients

(U.S. Senate Special Committee on Aging)

<http://aging.senate.gov/oas/hr59.htm>

The End of Life: Improving Care, Easing Pain and Helping Families

(Special Committee on Aging, U.S. Senate)

<http://aging.senate.gov/oas/hr54.htm>

Death Planning Made Difficult: The Danger of Living Trust Scams

(Special Committee on Aging, U.S. Senate)

<http://aging.senate.gov/oas/hr53.htm>

Suicide Prevention: Efforts to Increase Research and Education in

Palliative Care (HEHS-98-128)

<http://www.gao.gov/archive/1998/he98128.pdf>

Funerals and Burials: Protecting Consumers from Bad Practices

(Special Committee on Aging, U.S. Senate)

<http://aging.senate.gov/oas/hr48.htm>

and <http://aging.senate.gov/oas/hr49.htm>

Hospice and Nursing Homes Contractual Arrangements

(Office of the Inspector General, U.S. Department of Health and Human Services)

<http://oig.hhs.gov/oei/reports/oei-05-95-00251.pdf>

Articles and Foundation Reports

Financing End-of-Life Care: Challenges for an Aging Population February 2003

(Academy Health)

<http://www.hcfo.net/pdf/eolcare.pdf>

Patterns of Functional Decline at the End of Life (May 2003)

(Journal of the American Medical Association)

<http://jama.ama-assn.org/cgi/content/abstract/289/18/2387>

Advances in State Pain Policy and Medical Practice

(Last Acts)

<http://www.lastacts.org/files/publications/SPC05Pain.pdf>

Hospice Use Among Medicare Managed Care and Fee-for-Service Patients Dying With Cancer

(Journal of the American Medical Association)

<http://jama.ama-assn.org/cgi/content/abstract/289/17/2238>

Strengthening Nursing Education in Pain Management and End of Life Care

(Robert Wood Johnson Foundation)

<http://rwjf.org/reports/grr/032829.htm>

Pioneer Programs in Palliative Care

(Robert Wood Johnson Foundation)

<http://www.milbank.org/pppc/0011pppc.html>

The Management of Persistent Pain in Older People

(American Geriatrics Society)

http://www.americangeriatrics.org/education/manage_pers_pain.shtml

Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death (July , 2003)

(New England Journal of Medicine)

<http://content.nejm.org/cgi/content/short/349/4/359>

Research Initiatives to Improve End of Life Care

(Geriatric Times)

<http://www.geriatrictimes.com/g021221.html>

Academic Centers

Pain and the Law Website

(Center for Health Law Studies, Saint Louis University)

<http://www.painandthelaw.org/>

Institute on Palliative Care

(University of Ottawa, Canada)

<http://www.pallcare.org/english.htm>

Center to Advance Palliative Care

(Mt. Sinai School of Medicine)

<http://www.capcmssm.org/>

Department of Pain Medicine and Palliative Care

(Beth Israel Hospital)

<http://www.stoppain.org/>

Johns Hopkins Medicine Palliative Care

(Johns Hopkins University and Medical Center)

<http://www.hopkinsmedicine.org/palliativecare.html>

Professional Organizations

American Academy of Hospice and Palliative Medicine

<http://www.aahpm.org/>

American Board of Hospice and Palliative Medicine

<http://www.abhpm.org/>

American Hospice Foundation

<http://www.americanhospice.org/>

American Pain Society

<http://www.ampainsoc.org/>

American Society of Regional Anesthesia and Pain Medicine

<http://www.asra.com/>

Hospice Foundation of America

<http://www.hospicefoundation.org/>

National Hospice and Palliative Care Organization

<http://www.nhpco.org/>

Hospice and Palliative Nurses Association

<http://www.hpna.org/>

International Association for Hospice and Palliative Care

<http://www.hospicecare.com/>

National Association of Home Care

<http://www.nahc.org/>

Visiting Nurse Association of America

<http://www.vnaa.org/>

Journals

Innovations in End-of-Life Care

(Education Development Center)

<http://www2.edc.org/lastacts/>

American Journal of Hospice & Palliative Care®

<http://www.pnpco.com/pn01000.html>

Pain and Palliative Care Reporter

(Brazelon Center for Mental Health Law)

<http://www.painlaw.org/>

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